

and at worst is dismissive of our most basic human rights.

Ms Simms argues repeatedly that 'carers have a right to life'. No one in their right mind would dispute this. In fact, the salient point here is precisely that nobody has ever suggested depriving the carers of their lives, in the way that some people have suggested depriving the newborn handicapped of their lives.

Ms Simm's argument rests upon a false conflation of 'right to life' with 'right to a particular quality of life'. If, as she suggests, it were the case that the parents' right to life was at least equal to, and in immediate conflict with, the child's right to life, then there would indeed be a *prima facie* case for one of the parties to relinquish that right. If, that is, the child's continued existence was incompatible with the parents' continued existence, then we could at least start to think about who is going to have to die. But I have yet to hear of such a case.

It is indeed scandalous that parents, through lack of governmental and other support, are forced into a 'lifetime of caring' which is truly 'intolerable'. But this is not a matter of life and death, it is a matter of quality of life. They do not thereby have, as carers, lives that are not worth living. Ms Simms is wrong to say this as it would, if true, imply that they have no greater moral claim to life than the same handicapped infants whose projected quality of life renders them vulnerable to killing. They have, as carers, lives which are much poorer in quality than if they were not carers, or if others were involved in the caring. If, that is, governmental policies and public attitudes were different.

I would argue that a right to life is obviously more important than a right to a particular quality of life. It logically presupposes it, in that a given quality of life is unattainable if your life has been taken from you. But I am not arguing here for a simple play-off of rights with the more important ones winning. I am not, that is, arguing that carers ought to put up with present circumstances because their children's right to life is sacrosanct.

The conflict between rights of infants and rights of carers is caused, in the major part, by governmental policies and public attitudes. Ms Simms admits these as important variables in her references to hospital conditions, the difficulties in getting handicapped children adopted, and public spending levels. It is most unfortunate that she appears to acquiesce in these conditions, treating them as factors

beyond our control. When faced with harsh impositions and uncaring attitudes which depress the quality of peoples' lives and frustrate their caring impulses, is it better to resolve the impasse by killing people, or by changing those circumstances?

Ms Simms speaks of 'the real world that exists out there'. To deprive the weakest in that world of their most basic rights, on the grounds that a governmental or public attitude has deprived others of totally different rights, is a policy which lacks morality and courage as much as it lacks logical coherence.

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Response to Neale

SIR

Mr Neale argues that the right to life is more important than the right to a reasonable quality of life. I would disagree with this proposition, since the 'life' he talks about in the first instance may be barely more than a vegetable form of existence with hardly any brain function. Several of the severely handicapped young people I saw in the course of my investigation were in this sad and hopeless condition. He argues that it is the duty of their parents to abandon all hope of a normal life of their own in order to sustain such a being, who demands their total and unremitting attention for the foreseeable future as long as he or she remains at home.

I do not think that parents have any such duty nor do I admire those who allow themselves to become a human sacrifice in such a hopeless cause. If society as a whole takes Mr Neale's view of the matter, then society has to provide the total and very expensive care in perpetuity that such conditions demand. Society has no moral right to demand that the parents shoulder this burden on its behalf, which is what so often happens at present.

The ugly question of priorities therefore necessarily raises its head. Mr Neale blames 'governmental policies and public attitudes'. Given the dire state of Britain's economy and the stress under which the NHS and the social services labour, it is really fanciful to believe that the large sums of public money needed to give the very severely handicapped and their carers a worthwhile quality of life will be forthcoming in the lifetime of most of us taking part in this correspondence. Most people, as Mr

Neale notes, do not appear to believe that maintaining a mockery of life ought to be given priority over returning sick people to health. Far from thinking this deplorable I regard it as sensible and realistic. What is important is that the criteria on which these views about the quality of life of the very severely handicapped are based, should be clearly stated and publicly discussed in a rational way. Doctors should not, as they are sometimes forced to at present, have to make these decisions about life and death furtively and under the immediate pressure of lack of resources.

While profoundly disagreeing with Mr Neale on this point, I think he has raised a very important issue. Increasingly the argument in medical ethics on a variety of important matters does seem to be between the Sanctity of Life party versus the Quality of Life party. What both parties need to be honest about is in recognising that there are no longer enough social and medical resources to fulfill all needs and that some will inevitably have to be sacrificed to others. In a recent paper, Dr Andrew Whitelaw wrote:

'Neonatal intensive-care units have the ability to prolong the lives of infants with profound neurological abnormalities, including some who will never enjoy independent meaningful lives. Furthermore, neonatal intensive care is an expensive and scarce resource which is sometimes denied to viable infants because of shortages of nurses or equipment. Against this background, many paediatricians have practised selection in applying high-technology life-support techniques' (1).

My own impression is that the Sanctity of Life party has not yet recognised that in the real world such hard choices do have to be made.

References

- (1) Whitelaw A. Death as an option in neonatal intensive care. *Lancet* 1986; 2: 328-331.

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Funeral service

SIR

Your readers may be interested to hear of the funeral service arranged jointly by the University of Dundee Chaplaincy and the Department of Anatomy.

This service is attended by relatives